

# defining hope

## Study Guide



**CAROLYN JONES FILM • PRODUCED BY LISA FRANK**

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*Educational material created by Diana Mager, DNP, RN-BC, Associate Professor of Nursing, Fairfield University, for the American Nurses Foundation*



## USING THIS GUIDE

*Defining Hope* is a one-hour, eighteen-minute film. This guide was developed to stimulate audience reflection, conversation, and interaction. This guide highlights 14 brief video segments so that viewers may watch single segments of the film focused on particular topics.

The individual video segments can be viewed for free at [www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

Nurses can receive free contact hours for watching each video segment and completing the evaluation thanks to the generous support of Walden University. Walden University is accredited as a provider of continuing nursing education by the American Nurses Credentialing Center's Commission on Accreditation. For more information visit [www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

Each of the 14 segments is based on the following template:

Segment #1-14, Title, Length: Each segment is numbered, titled, and followed by the approximate length of run time in minutes for that segment.

### Objective/s

A minimum of one learning objective is included for each video segment.

### Summary

There is a brief overview of the segment followed by a description of the patient or nurse highlighted therein.

### Discussion Points

Each summary is followed by a suggested "discussion point" that the speaker/educator may use to initiate conversation or to present more insight into that segment.

### Discussion Question/s

Discussion points are followed by a minimum of two discussion questions designed to encourage reflection and discussion among audience members. Questions were developed to stimulate interaction; there are no "right" or "wrong" answers.

### Further Discussion/Points as Needed to Prompt Audience Interaction

Discussion questions are followed by further discussion points in the event that the audience

requires more prompting or encouragement to share ideas.

### Suggested Applicability to Nursing Courses and/or to Care Settings

This section provides suggested courses (nursing or other), as well as other care settings where educators may find value by embedding particular video segments into curriculum to highlight a point.

### Suggested Congruence with ELNEC® Modules

This section provides suggested End-of-Life Nursing Education Consortium (ELNEC)® modules where ELNEC® educators may find value by embedding particular segments into their curriculum. ELNEC® is a national education initiative to improve nursing education on end-of-life care. The project is administered by the American Association of Colleges of Nursing and City of Hope.

### Related Segments

Some segments are related to others presented elsewhere in the film. This section provides the titles of any related video segments.

### References

If materials or other sources were used within a section, a reference list is provided.

## OBJECTIVES

**By the end of this film, viewers will be able to:**

1. Discuss key factors that affect patient and family decision making about end-of-life care.
2. Differentiate between hospice and palliative care.
3. Compare and contrast the terms sympathy and empathy.
4. Discuss internal conflicts that people may encounter when making decisions about whether to pursue aggressive treatment for life threatening illnesses.
5. Describe the role of the nurse in palliative care/hospice settings.
6. Discuss how family members play a significant role in decision making surrounding care choices.

## ABOUT THIS GUIDE

Guide created by Diana Mager, DNP, RN-BC, Associate Professor and Director of Continuing Education, Kanarek Center for Palliative Care for Nursing Education, Marion Peckham Egan School of Nursing and Health Studies.

Guide made possible by the American Nurses Foundation with support from the Rita & Alex Hillman Foundation.

### The American Nurses Foundation

The American Nurses Foundation is dedicated to transforming the nation's health through the power of nursing. It helps nurses help people by supporting, recognizing and investing in the 4 million nurses across the United States. Learn more about the American Nurses Foundation and recognize nursing excellence at [www.givetonursing.org](http://www.givetonursing.org)

### The Rita & Alex Hillman Foundation

The Rita & Alex Hillman Foundation cultivates nurse leaders, supports nursing research and innovations, and disseminates new models of care—all critical to transforming our health-care system into one that is more patient-centered, accessible, equitable, and affordable; one that delivers the high-quality care patients need and deserve. Learn more about the Rita & Alex Hillman Foundation and our approach to nursing-driven innovation at [www.rahf.org](http://www.rahf.org)

## OTHER RESOURCES BY CAROLYN JONES

From the creators of *Defining Hope*, further film and narrative resources about nurses and nurses' care for the seriously ill can be found at:

[www.DyingInAmerica.org](http://www.DyingInAmerica.org), an interview project that examines the dying experience through the eyes of nurses.

[www.AmericanNurseProject.com](http://www.AmericanNurseProject.com), a multimedia initiative to elevate the voice of nurses in this country by capturing their personal stories through photography and film. A portion of all proceeds benefit a scholarship fund for nurse education through the **American Nurses Foundation**.

## THE FILM

The full film is available at [www.hope.film](http://www.hope.film). A portion of the proceeds from this documentary support programs that advance expertise in palliative nursing practice at the American Nurses Foundation and Jonas Nursing and Veterans Healthcare.

**For more information visit [www.hope.film](http://www.hope.film)**

## Video Segment #1

### Knowing It's the Right Thing (6 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits <https://waldenuniversitycne.rivvent.com/a/PBRWQX>



#### Objective

By the end of this video segment, viewers will be able to reflect on how end-of-life care decisions can affect patients and their family members.

#### Summary

Diane Ryan, RN, describes Calvary Hospital and her observations as an RN.

#### Patient Highlighted

Carole Bailey; chemotherapy no longer effective.

#### Discussion Point 1

Mrs. Bailey and her daughter appear to have accepted the fact that medical interventions such as chemotherapy will not cure her illness, prolong, or save her life at this point. They have opted to forego further chemotherapy and instead to pursue comfort measures.

#### Discussion Question 1

Reflect on the possible viewpoints and hopes of the varied players in this scene (Mrs. Bailey, her daughter, Diane the RN), and how they may be affected by this decision.

#### Further Discussion/Points as Needed to Prompt Audience Interaction

How does Mrs. Bailey appear to you? Is she calm? Comfortable? While she appears to be medicated and perhaps sedated, she still has enough pain that she doesn't want to be moved much. She has told her daughter that she doesn't want to leave her grandchildren, and her daughter has ensured that she can see their picture from her bed. Although she is quiet, does she appear sad? What might she be thinking? Does it appear to you that she has reached a stage of acceptance? Why or why not?



Mrs. Bailey's daughter speaks freely about the decision to stop the therapy and how hard her mother has fought her cancer battle. She is holding back tears and her face is flushed while she jokes and chats and refers to the photograph of her children. What might she be thinking? Does it appear that she has reached an acceptance stage?

Diane talks about her own future death, and how she wants it to happen. How do you think that her experiences to this point may have contributed to her wishes?

## Discussion Question 2

Sometimes people use the terms "hospice" and "palliative care" interchangeably, yet while they have similar attributes, they are different in ways. Discuss the differences and similarities between hospice and palliative care and how, according to Diane the RN, Calvary Hospital provides care to people in these situations.

## Further Discussion/Points as Needed to Prompt Audience Interaction

**Hospice** definition (According to the *End-of-life Nursing Education Consortium (ELNEC) Core Curriculum Guide*© [revised 2018]):

"Hospice is a team approach to provide care to people with life-threatening illness or injury and supports dignity of life, irrespective of how much time the person has (NHPCO, 2017). In addition, hospice: supports the patient through the dying process and the surviving family through the dying and bereavement process. Provides comprehensive medical and supportive services across a variety of settings and is based on the idea that dying is part of the normal life cycle. Provides care in the home, residential facilities, hospitals and nursing facilities, and other settings (e.g. prisons). Hospice cares for the terminally ill (prognosis of 6 months or less)."

**Palliative care** definition (According to the *End-of-life Nursing Education Consortium (ELNEC) Core Curriculum Guide*© [revised 2018]):

"The definition of palliative care in the United States described by the National Consensus Project (NCP, 2013) and the National Quality Forum (NQF, 2006) states:

"Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice."

## Discussion Question 3

Calvary Hospital is described by Diane the RN as a place where people go at the end-of-life and they know they will "never ever leave." She describes the hospital as a place where people who are dying can have dignity and can die in a peaceful, beautiful way. Discuss how a hospital such as Calvary varies from an acute care setting in terms of care provided, goals of care, and possible patient expectations when being admitted to Calvary or any similar hospital.

## Further Discussion/Points as Needed to Prompt Audience Interaction

What kind of skills, knowledge, and attitude does Diane the RN demonstrate as she cares for Mrs. Bailey?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Mental Health Nursing; Medical/Surgical Nursing; any course focused on communication, bereavement, ethical issues, quality of life, spirituality, family systems and/or culture. **Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## References

ELNEC-Core Curriculum® COH & AACN, 2007. Revised February, 2018.

National Consensus Project (NCP) for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care*, 3rd edition. Accessed November 16, 2017 from: <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013>

National Hospice and Palliative Care Organization (NHPCO). (2017). *NHPCO facts and figures: hospice care in America 2016*. Alexandria, VA: Author. Accessed November 16, 2017 from: <https://www.nhpco.org/hospice-statistics-research-press-room/facts-hospice-and-palliative-care>

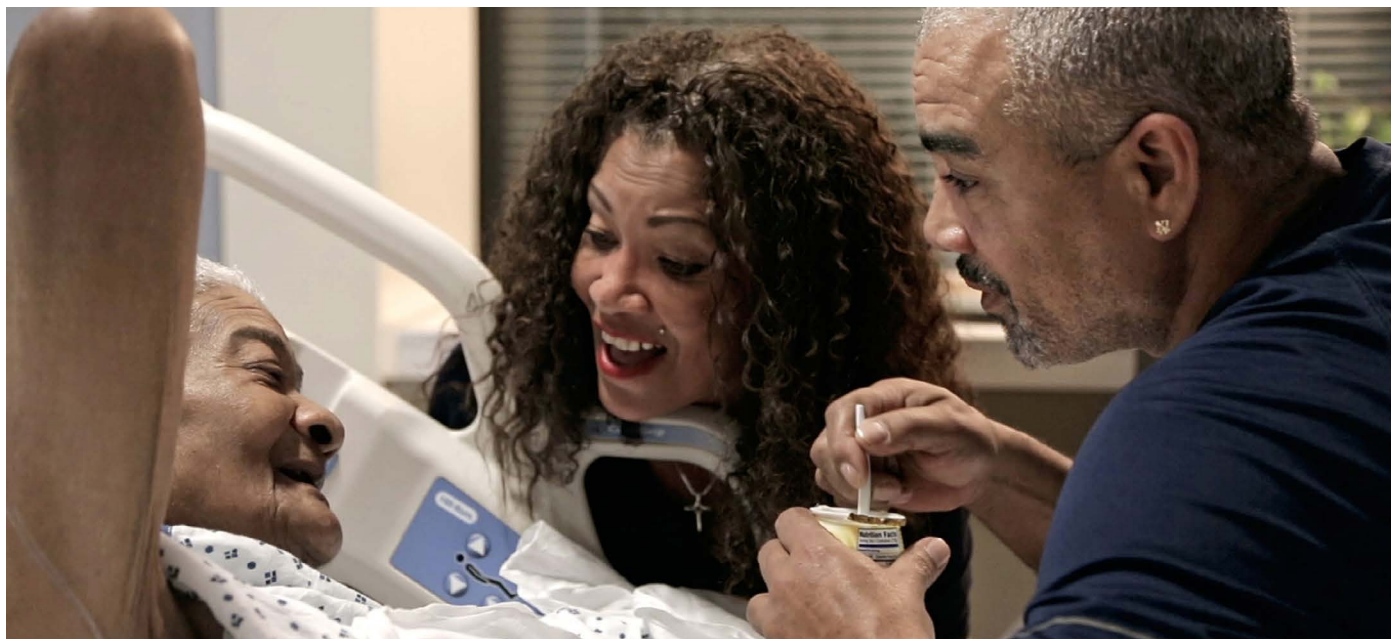
National Quality Forum (NQF). (2006). *A national framework and preferred practices for palliative and hospice care quality*. Washington DC: Author. Accessed November 16, 2017 from: [http://www.qualityforum.org/publications/2006/12/A\\_National\\_Framework\\_and\\_PREFERRED\\_Practices\\_for\\_Palliative\\_and\\_Hospice\\_Care\\_Quality.aspx](http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx)

## Video Segment #2

### Remember this Song? (6:10 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits <https://waldenuniversitycne.rievvent.com/a/TRTAOD>



#### Objective

By the end of this video segment, viewers will be able to discuss examples of non-medical comfort measures that can bring peace and joy to patients.

#### Summary

This scene takes place in the hospital where Mrs. Marrero is in bed with her two adult children present. They are singing together.

#### Patients Highlighted

Nina Marrero, diagnosed with Alzheimer's disease six years ago, and her husband Raoul, diagnosed with end-stage cancer.

#### Discussion Points

Mrs. Marrero appears to be rather despondent. Her daughter mentions that she has had Alzheimer's disease for six years and that one day she just stopped talking. She says she wishes she could just have her mom back. Then she starts singing to her mother, and suddenly Mrs. Marrero starts singing along in Spanish. It is so touching that all the medications we have available to us cannot restore memory to Mrs. Marrero, and yet a beautiful song in her native tongue rolls out like she is a young woman again.

#### Discussion Question 1

What are some ways that we can ensure people are treated like people, first, and not just as patients?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

What are some examples of non-medical comfort measures that may be used to help persons feel safe, connected, or secure in their physical setting, but also in their emotional and spiritual place in time? (examples may include particular songs/music, pictures, mementos, religious artifacts, paintings, an article of clothing, a blanket or pillow, a tape of birds singing, a scent). How can a nurse support family involvement so they can have meaningful, mutually enriching and comforting interactions?

## Discussion Question 2

Reflect upon a situation where you may have thought that a patient could not see, hear, or perhaps understand you, and then suddenly they said or did something that surprised you. Can you share that situation and how it made you feel? What did you learn as a result of that encounter?

## Further Discussion/Points as Needed to Prompt Audience Interaction

What did you learn as a result of watching the encounter between Mrs. Marrero and her family? What effect do you think this encounter may have had on the family?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Introduction to Nursing; Geriatric Nursing; Medical/Surgical Nursing; Mental Health Nursing; and any courses focused on culture, communication, spirituality. **Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication.



## Video Segment #3

### A Little Bit Makes the Biggest Difference (6:10 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/DCLIOQ>



#### Objective

By the end of this video segment, viewers will be able to discuss difficulties that can arise when patient wishes are more idealistic than realistic.

#### Summary

Diane Ryan, RN, describes how talking about comfort care at the end of life, even if only a bit, can make a huge difference in the person's dying experience.

#### Patients Highlighted

Barbara Stephenson, 67-year-old woman with renal cell cancer and Myasthenia gravis.

#### Discussion Points

Ms. Stephenson is a woman of faith. She discusses how she cared for people during the 1980's AIDS crisis and how she tried to comfort people with healing words. She tells us that she is currently using her own words "on herself." Her main goal is to go home.

#### Discussion Question 1

In spite of the collaborative care Ms. Stephenson is receiving at Calvary Hospital, she prefers to go home where she lives alone. Discuss how her decision to go home may affect her longer term outcomes, and whether or not that should play a role in the decision.

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Do you think that she will not live as long if she leaves the hospital setting and has to deal with all of her medical issues more independently and without the support of the inter-collaborative hospital team? If leaving the hospital will shorten her life, do you feel that it is still acceptable for her to make this choice?

## Discussion Question 2

Ms. Stephenson speaks freely about her fearlessness about death. She considers it a transition from one place to another. How do you see her religious background playing a part in her ability to accept or even rationalize the end of her life on earth?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Do you think the fact that she cared for others at the end of their lives makes her more realistic in terms of her own outcomes? Do you believe that her faith gives her strength and removes fear about her remaining days and/or about her impending death?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Medical/Surgical Nursing; Mental Health Nursing; Home Health/ Community Nursing; and any course focused on communication, safety, discharge planning; spirituality and/or culture.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## Related Video Segment

#5: I'm Going Home.

## Video Segment #4

### I'm Here Now (5:56 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/GRUIDD>



#### Objective

By the end of this video segment, viewers will be able to reflect on the dichotomy that may occur when patients try to be outwardly strong for their families, yet inwardly face fear or sadness.

#### Summary

This vignette exemplifies a person who, although nearing the end of life, states she wants to use every minute she has left to really live. She wants her adult children to remember her with joy, yet when she is alone she cries and mourns her losses.

Diane Ryan, RN, shares her own 2013 journey with a diagnosis of metastatic ovarian cancer. She reflects on how she works with patients who are of similar age and diagnosis to herself, who have died on her unit.

#### Patient Highlighted

Carmen Hernandez with her recently married adult daughter.

#### Discussion Points

At times it may be difficult to separate a nurse's professional perspective from her/his personal feelings about a patient or situation. Many factors, both conscious and subconscious may contribute to this phenomenon. For example, a patient who reminds the nurse of a family member or friend may affect the therapeutic relationship in some way. Having the same diagnosis as a patient may also be a factor in nurses' ability to separate their personal thoughts from the care they render.

#### Discussion Question 1

Reflect on how you, as a provider, care for patients who may have similar situations, diagnoses or illnesses as yourself. How do you deal with parallel personal issues when caring for patients?

## Further Discussion/Points as Needed to Prompt Audience Interaction

What kinds of support systems exist for nurses, especially for those working in high stress areas? (examples may include support groups, individual counseling, employee health services, yoga/exercise or other forms of stress relief, socializing with colleagues outside of work to laugh/talk, allowing oneself to “debrief” with others while at work, making time to enjoy family/friends/pets/hobbies). Do you address your fears in some way? Deny them? Wall them off?

## Discussion Question 2

When Diane is talking to Mrs. Hernandez, they are both crying. Do you think that Diane’s own situation has contributed in some way to her empathy for her patients?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Do you feel that Diane may be having some difficulty in separating her personal journey with those of some patients? Why or why not?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, bereavement, ethical issues, spirituality, quality of life, family systems and/or culture.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement; Final Hours.

## Related Video Segments

(These segments are related to Diane the nurse’s journey): #9: I’d Rather Be Running; #14: Every Day Is a Special Day.



## Video Segment #5

### I'm Going Home (3:13 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/QPOSLS>



#### Objective

By the end of this video segment, viewers will be able to discuss difficulties that may arise when patient wishes seem more idealistic than realistic.

#### Summary

Ms. Stephenson's health care team is working to develop a discharge plan so that she may go home. Despite her strong desire to return to life outside of the hospital and to resume her normal activities, she will require many services and support systems to be successful.

#### Patients Highlighted

Barbara Stephenson, 67-year-old woman with end stage renal cell cancer and Myasthenia gravis.

#### Discussion Points

Mrs. Stephenson says, "You have to believe in something." When asked what she will do first when she gets home she quickly replies, "play golf." She is quite weak, admits that she can't walk well, and she has a number of medical devices attached to her.

#### Discussion Question 1

Reflect on Mrs. Stephenson's statements about playing golf and returning to preaching when she gets home. What do you think prompts her to reach so high regarding her functional abilities?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Do you think she is being unrealistic? Idealistic? Or is she trying to aim high to be positive and to believe in something as she has previously stated?

#### Discussion Question 2

If you were the nurse caring for Mrs. Stephenson, how would you respond when she states that her goal is to play golf?



## **Further Discussion/Points as Needed to Prompt Audience Interaction**

Would you validate her goals? Would you talk to her about safety? Would you fear that you would diminish her hope if you took a more realistic approach?

## **Suggested Applicability to Nursing Courses and/or to Care Settings**

**Courses:** Palliative/Hospice Care; Mental Health Nursing; Home Health/Community Nursing; Medical/Surgical Nursing; and any course focused on communication, safety, discharge planning; spirituality and/or culture.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## **Suggested Congruence with ELNEC® Modules**

Palliative Nursing Care; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## **Related Video Segment**

#3: A Little Bit Makes the Biggest Difference.

## Video Segment #6

### Hospice Is Hard to Accept (7:39 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits <https://waldenuniversitycne.rivvent.com/a/PTCIVV>



#### Objective

By the end of this video segment, viewers will be able to: discuss common misperceptions about hospice care; reflect upon the difficulties that may arise when a patient and her/his significant other have different views about end-of-life care decisions.

#### Summary

Gilbert Oakley, RN, a visiting hospice nurse in New York, is conducting a home hospice visit to a patient and his wife. He discusses his role as a hospice nurse, and he sits with the couple and interviews them about their future health care wishes.

#### Patients Highlighted

Bert Cohen, 95-year-old living at home with his wife, and receiving hospice services. Their adult children, though very supportive, are not there according to Mrs. Cohen.

#### Discussion Point 1

There are many varied fields within nursing, including hospice and palliative care. Reflect on Gilbert the nurse's comments about being a hospice nurse. He talks about the hospice team as being "granola, touchy-feely, and really nice." He mentions the team singing and burning incense.

#### Discussion Question 1

How do Gilbert's reflections about hospice and the care team fit with your vision of what hospice means?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Do you think that people in general, and/or nurses may have preconceived ideas, generalizations, expectations, or fears about working or being cared for in a hospice/palliative care setting? If so, give examples. What specific care did you see Gilbert provide?

#### Discussion Point 2

Mr. Cohen and his wife have very different views about him dying at home. While he wishes to continue to live "a fairly normal life" he is expressing a desire to avoid hospitalization, and to die at home when the time comes. However, Mrs. Cohen talks about the need to go to the hospital "if it makes you better."

## Discussion Question 2

How does Gilbert deal with the conflicting opinions between Mr. and Mrs. Cohen regarding hospitalization versus dying at home?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Gilbert has an open discussion with the couple, and while he respectfully acknowledges Mrs. Cohen, he clearly supports Mr. Cohen's wishes. How do the wishes of Mrs. Cohen play a role here? Should they play a role in whether her husband stays at home or whether he gets admitted to the hospital?

## Discussion Question 3

Mrs. Cohen says, "From what he (the RN) tells me, I don't want to think about the future." Regarding hospitalization, she says, "If something important needs to be done, it should be done." What factors play into Mrs. Cohen's thoughts on her spouse's potential hospitalization versus his staying at home?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Do you think that Mrs. Cohen fears her ability to care for Mr. Cohen at home if he deteriorates? (She has stated her children are supportive but are "not here." Or do you think that she feels that the hospital can "help him more?" Is she being unrealistic, or is she trying to preserve his health, or perhaps her own, by wishing to hospitalize him?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Geriatric Nursing; Nursing Roles; Home Health/Community Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, ethical dilemmas, and/or family systems. **Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## Related Video Segment

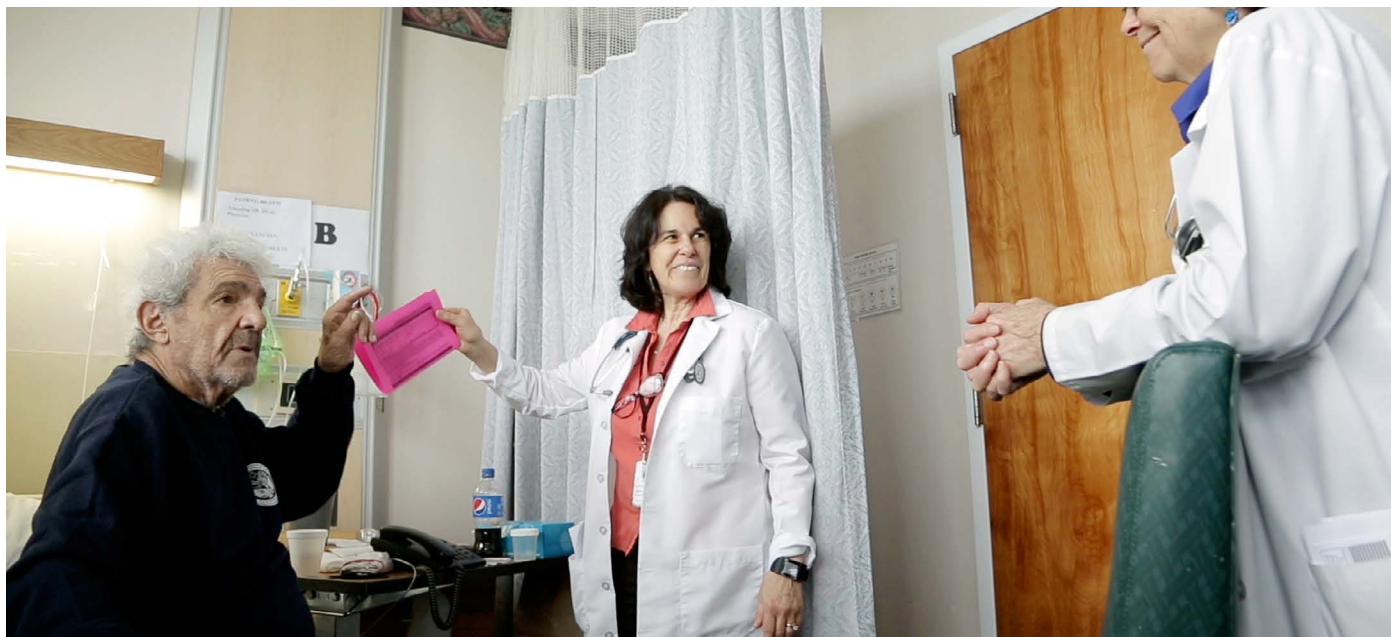
#8: Sympathy Versus Empathy.

## Video Segment #7

### I Signed the Papers (6:28 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits <https://waldenuniversitycne.rievvent.com/a/TOCAGO>



#### Objective

By the end of this video segment, viewers will be able to discuss various ways that patients sometimes cope with difficult decisions.

#### Summary

This vignette highlights Mr. Bilotti, who is being discharged from the hospital to his home where he lives alone. He describes the love between him and his wife of 60 years, who has predeceased him.

#### Patients Highlighted

Rudy Bilotti, WWII veteran with kidney failure who has signed the necessary paperwork to refuse dialysis, and to implement “Do Not Resuscitate” status.

#### Discussion Points

Mr. Bilotti seems to be somewhere in the middle of acceptance and fear regarding his situation, at times joking while at other times becoming teary-eyed throughout the interview.

#### Discussion Question 1

Reflect upon Mr. Bilotti’s talking points, and describe why you believe he may have signed the paper. What are some of the conflicting points of view that he portrays?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

When asked if he is afraid to die, what is his response? He states, “Who’s not afraid to die?” implying that he has fear. Yet he jokes about being the “happiest corpse in the cemetery.” What do you think he means by these comments? If you were in his situation, what do you think you would do?

#### Discussion Question 2

What role do you believe Mr. Bilotti’s deceased wife plays in his acceptance of his prognosis?

**Further Discussion/Points as Needed to Prompt Audience Interaction**

Mr. Bilotti talks about how he would have rather lost an arm than to have lost his wife. How do you think the loss of such a prominent figure in his life may be affecting his desires to refuse extraordinary measures to keep him alive?

**Suggested Applicability to Nursing Courses and/or to Care Settings**

**Courses:** Palliative/Hospice Care; Introduction to Nursing; Home Health/Community Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, advanced care planning (Do Not Resuscitate orders, POLST or MOLST orders), discharge planning, access to care, and/or family systems.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

**Suggested Congruence with ELNEC® Modules**

Palliative Nursing Care; Symptom Management; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.



## Video Segment #8

### Sympathy Versus Empathy (4:05 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/VNILMN>



#### Objective

By the end of this video segment, viewers will be able to: discuss factors that may contribute to a patient or family's potential denial regarding the current status of a medical condition; and discuss the differences between having sympathy versus having empathy for patients.

#### Summary

This segment takes place in the home of Mr. and Mrs. Cohen with Gilbert, the visiting hospice nurse, conducting a visit. The focus of the visit is the discussion of Mr. Cohen "slowing down" as the patient replies, "I'm glad when I move at all."

Gilbert Oakley, RN, a hospice home care nurse, talks about how he "feels bad" for people, but that he doesn't "feel sorry" for them, and how he doesn't want them to feel sorry for themselves. He reflects on terminal illness in general, and how to best spend one's last days.

#### Patient Highlighted

Bert Cohen, 95-year-old living at home with his wife, and receiving hospice services. He is sleeping more and slowing down. Their adult children, though very supportive, are not there according to Mrs. Cohen.

#### Discussion Points

When talking about the need for a hospital bed, Mrs. Cohen sounds adamant when she states "He doesn't need it yet." The nurse is trying to teach him how to get into his bed with less difficulty; however, he is moving very slowly.

#### Discussion Question 1

What are some of the factors that may be contributing to Mrs. Cohen refusing the need for a hospital bed?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Many factors contribute to why people choose to accept equipment, services, and support. Although Mrs. Cohen may be exhibiting denial about the progression of Mr. Cohen's weakness, she later admits that he has become so weak that she has

recommended a wheelchair and he has refused to use one. How may the acceptance of medical equipment bring unwanted reality to a situation like the Cohens'? What may be other reasons that people refuse such equipment? (Examples include cost, limited room/space, aesthetic look to the room/home, desire to avoid the appearance of a hospital/sickness/death; it may act as a reminder that a loved one is sick or dying.)

## Discussion Question 2

If you were the nurse in the Cohen's home during this discourse, what might you have said to Mr. Cohen about accepting a hospital bed in the home? To Mrs. Cohen?

## Discussion Points

Although Gilbert does not use the words "sympathy" or "empathy," his reflections portray these two very different concepts.

## Discussion Question 3

What do you think Gilbert means when he says "I don't feel sorry for my patients?"

## Further Discussion/Points as Needed to Prompt Audience Interaction

Do you think that by saying "I don't feel sorry for my patients" that the nurse is uncaring in some way? What are the definitions of *sympathy* versus *empathy* and how do they relate to this vignette? While the words and their meanings are close, and sometimes are used interchangeably, they are different. *Empathy* tends not to imply pity for another person, whereas sometimes *sympathy* may imply this (see Merriam-Webster Dictionary definitions below).

**Sympathy:** "the feeling that you care about and are sorry about someone else's trouble, grief, misfortune, etc.: a sympathetic feeling." (Merriam-Webster Learner's Dictionary, 2017).

**Empathy:** "the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another of either the past or present without having the feelings, thoughts, and experience fully communicated in an objectively explicit manner." (Merriam-Webster Dictionary, 2017)

## Discussion Question 4

How do you differentiate *sympathy* and *empathy* in your own words?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Introduction to Nursing; Nursing Roles; Geriatric Nursing; Home Health/Community Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication and/or family systems. **Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## Related Video Segment

#6: Hospice Is Hard to Accept.

## References

Merriam-Webster Learner's Dictionary (2017). Merriam-Webster, Incorporated. Sympathy. Retrieved from: <http://www.learnersdictionary.com/definition/sympathy>

Merriam-Webster Dictionary (2017): Merriam-Webster, Incorporated. Empathy. Retrieved from: <https://www.merriam-webster.com/dictionary/empathy>

## Video Segment #9

### I'd Rather Be Running (5:37 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/HLKPEA>



#### Objective

By the end of this video segment, viewers will be able to reflect on how personal experiences, illnesses, or events may affect health care providers in different ways than lay people.

#### Summary

Diane Ryan, an RN working on the hospice units of Calvary Hospital, reports that her ovarian cancer, first diagnosed in 2013, has returned. She is asking questions about hair loss, and is discussing her current situation and the potential outcomes with her sister as she receives chemotherapy.

#### Patient Highlighted

Diane, young mother, wife, and hospice nurse. First diagnosed with ovarian cancer in 2013, she was told during the filming of *Defining Hope* that cancer has returned.

#### Discussion Points

Diane seems to have a realistic view of her possible death related to the recurrence of ovarian cancer. She states, “... being a nurse and working with all these cancer patients ... and knowing what can happen, is my disadvantage.” She talks about not being afraid to die, but rather caring more about how she dies, and her desire for comfort and quality of life versus quantity.

#### Discussion Question 1

How do you think Diane has come to such a clear vision of her future end-of-life care decisions?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

What kinds of experiences (personal and professional) may have either helped or hindered Diane in reaching decisions regarding end-of-life care choices? (Points to discuss: she has witnessed many patients die after recurrent cancer diagnoses; is she realistic? Idealistic? Has she gained strength or lost hope?) Additionally, Diane states that she has seen peaceful and beautiful deaths, yet we may assume she has also seen the opposite. Discuss how her role as a nurse and also as a patient may influence her choices.

## Discussion Question 2

Often we hear nurses say, “I know too much” when it comes to personal medical concerns. How do you deal with the vast knowledge that you have, and how it may sometimes affect your life?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Do you diagnose yourself with the worst case scenario each time you don't feel well? Do you ignore symptoms? Or do you frequent your provider's office with many concerns? How do you cope with having all the knowledge and yet not let it hamper your life?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Introduction to Nursing; Nursing Roles; Home Health/Community Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, quality of life.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## Related Video Segments

#4: I'm Here Now; #14: Every Day Is a Special Day.



## Video Segment #10

# It's Not Always About Death, It's About Living Life to the Fullest (1:54 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/VUDMNR>



### Objective

By the end of this video segment, viewers will be able to discuss how a recurrent illness may warrant discussions about palliative care choices.

### Summary

This segment opens with a nurse knitting with a young woman who has been diagnosed with a recurrent brain tumor. The nurse describes palliative care as not being about death, but rather about living life to the fullest and eliminating burdens.

Deborah LaFond is a nurse practitioner who has worked at Children's National Hospital for 24 years. The majority of her patients have been diagnosed with brain tumors, nearly 50 percent of whom are not cured.

### Discussion Points

Deborah speaks to the misperceptions about palliative care. She states that the word "palliative" is defined as "easing the burden" and says that burdens can come in many forms including physical, spiritual, financial, and others.

**Palliative care** as defined by the *End-of-Life Nursing Education Consortium Core Curriculum (ELNEC) Guide*® (revised, Feb. 2018):

"Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice."  
(NCP, 2013; NQF, 2006)

### Discussion Question 1

Reflect on the definition of palliative care. Based on this definition, how would you explain palliative care in your own words to the family of a terminally ill child?



## Further Discussion/Points as Needed to Prompt Audience Interaction

**Activity:** Ask participants to sit in groups of three. Ask one person to role play an RN and the others to role-play family members of a terminally ill person. Ask them to take turns in the RN role and to explain to the “family” what palliative care is in a way that they can understand.

## Discussion Question 2

Reflect upon a patient you cared for who chose to live life to the fullest, despite being near the end of their life. Can you share that story?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Nursing Roles; Home Health/Community Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, quality of life, and/or family systems.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## Related Video Segments

#11: Is It Worth It? I Don't Know ... ; #13: Quality Versus Quantity

## References for Palliative Care Definition

ELNEC-Core Curriculum® COH & AACN, 2007. Revised February, 2018.

National Consensus Project (NCP) for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care*, 3rd edition. Accessed November 16, 2017 from: <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013>

National Quality Forum (NQF). (2006). *A national framework and preferred practices for palliative and hospice care quality*. Washington DC: Author. Accessed November 16, 2017 from: [http://www.qualityforum.org/publications/2006/12/A\\_National\\_Framework\\_and\\_PREFERRED\\_Practices\\_for\\_Palliative\\_and\\_Hospice\\_Care\\_Quality.aspx](http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx)

## Video Segment #11

### Is It Worth It? I Don't Know ... (10:25 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/KQXWLI>



#### Objective

By the end of this video segment, viewers will be able to reflect upon how the wishes and beliefs of adult family members may influence their children's care wishes.

#### Summary

This segment highlights a young woman discussing her experiences with a recurrent brain tumor. She speaks about how she felt when she was first diagnosed, how she uses journaling to help her cope, and how she goes on to face treatment for the recurrence. She and her family struggle with her memory loss as a possible long term disability.

#### Patient Highlighted

Alena Sydnor, young woman first diagnosed with a brain tumor in 8th grade. She has had several surgeries and, as a result, suffers from memory loss.

#### Discussion Point

Prior to having her second brain surgery, Alena is worried about the possibility of memory loss. She and her family have to balance the risk versus benefits of doing the surgery that could save her life, yet alter her memory for the rest of her life.

#### Discussion Question 1

What are some of the considerations that Alena and her family might be struggling with as they weigh benefits versus risks of brain surgery?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Both Alena and her family must have had a difficult decision to make when one alternative is likely death (without surgery), while the other is to possibly awaken from surgery not recognizing her family or remember her past.

#### Discussion Question 2

Do you feel that Alena is satisfied with her decision? Is her mother? Her sister? Why or why not?

**Further Discussion/Points as Needed to Prompt Audience Interaction**

Alena's mother is seen at the end of the vignette asking herself "Is it worth it? I don't know." How does Alena seem to feel regarding her outcomes?

**Suggested Applicability to Nursing Courses and/or to Care Settings**

Courses: Palliative/Hospice Care; Pediatric Nursing; Introduction to Nursing; Home Health/Community Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, quality of life, and/or family systems. Care Settings: Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

**Suggested Congruence with ELNEC® Modules**

Palliative Nursing Care; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

**Related Video Segments**

#10: It's Not Always About Death, It's About Living Life to the Fullest; #13: Quality Versus Quantity.

## Video Segment #12

### I Said ‘Yes’ Because I Want to Live (3:08 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/LGMNCW>



#### Objective

By the end of this video segment, viewers will be able to discuss palliative care in relation to a long term illness or condition.

#### Summary

This segment showcases a young boy who describes that his “proteins were escaping from his body,” requiring that he receive a heart transplant in order to live. He admits that he cries sometimes and his mother comforts him, and that he wants to become a nurse as a result of all he’s been through.

#### Patient Highlighted

Jose, 12-year-old who has undergone a heart transplant 3-4 months prior to filming his segment.

#### Discussion Point

Jose states that he said “yes” to the heart transplant because he still wants to be alive. While there is no indication in the film that Jose is dying, as health care professionals we are aware that the long term effects of organ transplant, anti-rejection medications, and other confounding factors can be debilitating and daunting, especially for a young boy.

#### Discussion Question 1

How can palliative care be helpful to a family in Jose’s situation?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Think about the definition of *palliative care*. Palliative care as defined by the *End-of-Life Nursing Education Consortium Core Curriculum (ELNEC) Guide*© (revised, Feb. 2018):

“Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.” (NCP, 2013; NQF, 2006)

What are some of the needs Jose and his family may experience as a result of his heart transplant and the long-term care that he will require? (Examples include financial burdens, medication side effects [one can see he has the characteristic facial swelling common with steroid use], fear of organ rejection, need for re-hospitalization, possible death).

## Discussion Question 2

Reflect on what you might say to Jose when you hear him say that sometimes he cries.

## Further Discussion/Points as Needed to Prompt Audience Interaction

What kinds of questions would you ask him about his crying? Do you think Jose would benefit from a referral to another health care professional? Or to someone else such as a spiritual/religious figure in his life?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Pediatric Nursing; Introduction to Nursing; Mental Health Nursing; Medical/Surgical Nursing; and any course focused on communication, growth and development, and/or family systems.

**Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## References for Palliative Care Definition

ELNEC-Core Curriculum© COH & AACN, 2007. Revised February, 2018.

National Consensus Project (NCP) for Quality Palliative Care. (2013). *Clinical practice guidelines for quality palliative care*, 3rd edition. Accessed November 16, 2017 from: <https://www.nationalcoalitionhpc.org/ncp-guidelines-2013>

National Quality Forum (NQF). (2006). *A national framework and preferred practices for palliative and hospice care quality*. Washington DC: Author. Accessed November 16, 2017 from: [http://www.qualityforum.org/publications/2006/12/A\\_National\\_Framework\\_and\\_PREFERRED\\_Practices\\_for\\_Palliative\\_and\\_Hospice\\_Care\\_Quality.aspx](http://www.qualityforum.org/publications/2006/12/A_National_Framework_and_PREFERRED_Practices_for_Palliative_and_Hospice_Care_Quality.aspx)



## Video Segment #13

### Quality Versus Quantity (4:27 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/DMPIFU>



#### Objective

By the end of this video segment, viewers will be able to reflect upon how the wishes and beliefs of adult family members may influence their children's or sibling's care wishes.

#### Summary

After having a second surgery for a recurrent brain tumor, a young woman is struggling with memory loss. She meets with a health care professional to develop ways to improve her quality of life. She has refused radiation after the surgery, as her sister states that they are considering what is the most important: the quality of life remaining, versus the quantity, or number, of years of life remaining.

#### Patients Highlighted

Alena Sydnor, young woman first diagnosed with a brain tumor in 8th grade. She has had several surgeries and, as a result, suffers from memory loss.

#### Discussion Point

Alena's mother has ongoing concerns about her daughter's future ability to care for herself. Together, Alena and her family decide that Alena will forego radiation because of the possibility of further memory loss. Alena's sister openly states that she'd rather have the years left with Alena to be of better quality, than to have her for longer without being able to function.

#### Discussion Question 1

Alena cries when her sister speaks about quality versus quantity of life. What do you think is going through Alena's mind?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Does it appear that Alena feels the same way about quality versus quantity? Do you think she may feel guilty, or feel like a burden to her family? If you were present during this conversation, what might you have said to Alena when witnessing her tears as her sister spoke? (Examples may include, “Alena, I see you are crying. Can you share what you are feeling right now?”)

## Discussion Question 2

Discuss some of the difficulties that could arise surrounding care decisions when your patient is a child or a minor.

## Further Discussion/Points as Needed to Prompt Audience Interaction

There are many factors to consider. (Examples include legal and ethical ramifications, child/minor’s maturity level and level of understanding of the situation, difficulty for a parent to make a decision to stop lifesaving interventions.) What are some others? What could the nurse do to assist Alena and her family in making such difficult decisions and then to live with the results of those decisions?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Introduction to Nursing; Home Health/Community Nursing; Mental Health Nursing; Pediatric Nursing; Medical/Surgical Nursing; and any course focused on communication, long term care, quality of life, and/or family systems. **Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement.

## Related Video Segments

#10: It’s Not Always About Death, It’s About Living Life to the Fullest; #11: Is It Worth It? I Don’t Know ...

## Video Segment #14

### Every Day Is a Special Day (6:54 min.)

[www.hope.film/study-guide-videos](http://www.hope.film/study-guide-videos)

For CNE credits: <https://waldenuniversitycne.rievent.com/a/HFRIWF>



#### Objective

By the end of this video segment, viewers will be able to reflect upon how a health care provider's personal journey can influence, or be influenced by their professional experiences.

#### Summary

In this segment, Diane Ryan, an RN, describes her personal journey through recurrent ovarian cancer and chemotherapy. She states that her second round of chemotherapy made her very sick and did not work. She explains that she was going to stop treatment, however she was offered a milder regimen that she accepted after considering her young children.

#### Patients Highlighted

Diane Ryan, young mother, wife, and RN who cares for patients on a hospice unit. She is currently on a third chemotherapy regimen despite her past decision to stop treatment.

#### Discussion Point

Diane has made it very clear that she is accepting of her own death sometime in the future, but that she wants to be comfortable.

#### Discussion Question 1

Reflect upon Diane's journey both as a nurse and as a patient. How are her experiences reflected in the decisions she is making in her own cancer battle?

#### Further Discussion/Points as Needed to Prompt Audience Interaction

Diane is transparent about her level of peace regarding her own possible death, but also her strong desire for comfort at the end of life. Do you think this transparency is helpful or difficult for her husband? Her family? Why or why not?

## Discussion Question 2

Do you think that Diane's returning to work is helpful or harmful for maintaining her quality of life?

## Further Discussion/Points as Needed to Prompt Audience Interaction

Diane has stated in the past that she loves her job; she has also stated that she has witnessed people with similar diagnoses die from the same illness that she has. What are your thoughts about her return to work?

## Suggested Applicability to Nursing Courses and/or to Care Settings

**Courses:** Palliative/Hospice Care; Introduction to Nursing; Nursing Roles; Home Health/Community Nursing; Mental Health Nursing; and any course focused on communication, spirituality, quality of life, and/or family systems. **Care Settings:** Orientation and/or in-service programs for health care providers in primary, acute, long term, hospice/palliative care, and/or home care settings.

## Suggested Congruence with ELNEC® Modules

Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues in Palliative Care Nursing; Cultural/Spiritual Considerations in End-of-Life Care; Communication; Loss, Grief, Bereavement; Final Hours.

## Related Video Segments

#4: I'm Here Now; #9: I'd Rather Be Running.